

Family TO Family

bulletin

Reaching out to Washington families who have children—birth to 6—with disabilities

Recognizing and celebrating the uniqueness and diversity of families



Infant/Toddler Early Intervention Program

SUMMER 2000

Greetings from Family Leadership Team

By Karen Lindsay,
Chair
Family Leadership Team (FLT)

Let me be the first to welcome you to the first Family to Family newsletter. I would like to give you a little background about myself, the Family Leadership Team, and the Family to Family Newsletter.

My name is Karen Lindsay and I live in Moses Lake, Washington. I am the parent of four children, three girls and a son. When my son, Nic was eight weeks old he contracted Group Strep B Meningitis. As a result he is blind, has CP tendencies and is developmentally delayed. When Nic was four months old he began receiving birth to three Early Intervention services. On the day my son began receiving service I was asked if I wanted to be on the County Interagency Coordinating Council (CICC). Like many of you I had no idea what the CICC was or did. My son's teacher explained that it was where representatives from all the agencies who work with children ages birth to three came together to make sure that all children who need early intervention services receive them. I was told that it was really important the CICC had parent input, so of course I agreed. The very first CICC meeting I attended I was the only parent in attendance. Therefore, any time a question came up. I was asked what I thought. What I really thought, was six months ago, I had healthy newborn twins, and, now I'm sitting in a room with twenty-five people I've never seen before being asked how parents feel about issues I've never heard before. Yes, my head was spinning. After a few months I began to grasp what county issues were and understood the terms being used.

In January 1997, just as my twins were turning a year old, I applied and was appointed by the Governor to the State Interagency Coordinating Council (SICC). In 1998

I was part of a team from Washington chosen to attend a National Parent Leadership Training. This team returned with a plan for increasing parent involvement in Washington State. They made a recommendation to the SICC to form a Family Leadership Team as a standing committee. Thus the Family Leadership Team I chair was born. The Family Leadership Team is comprised of the State ICC parent representatives as well as other committed parents from around the state. We work together as a team on many levels to ensure that parent perspectives are heard. The Family Leadership Team has worked on several projects such as public awareness and "Conversations With Families". Conversations with Families are State and County forums held to hear families views on Early Intervention Services their family has received. The Family Leadership Team makes recommendations to the SICC based on information they are hearing from families around the state. The recommendation for the Family to Family Newsletter was made by the Family Leadership Team as a way to improve getting information to families about early intervention services and resources at a state and national level. FLT members are developing the Family to Family newsletter.

The Family Leadership Team hopes you will contact us with topics or questions you might have as families of young children who have disabilities and/or developmental delays. The Family Leadership Team hopes you enjoy this our first issue of Family to Family as well as future issues. The next newsletter theme will be emotional support for families.

If you are interested in participation, or have questions, please contact Kathy Blodgett at (360) 902-8494 or e mail: BlodgetKA@dshs.wa.gov

Family perspectives Ginger Kwan

You have to be quick on your feet to catch our first featured Parent, **Ginger Kwan**. She is one busy lady! Ginger is married to Victor, an accountant, and she is the active mom of three children, two daughters, 2-1/2 and 7, and 4-year-old son, Mickle, who experiences autism. We asked Ginger to give us her family's perspective on their experience with the birth to three early intervention services.

We first connected with the early intervention system after Mickle was diagnosed with autism at 22 month of age, Nov. 1997. Our doctor did not refer us to early intervention services. We had a wonderful public health nurse, Hannah, who connected us to Kidcare, the Child Find entity in King County. There, we talked with Sandy who became our FRC and referred us to Children's Therapy of Kent's Satellite branch.

We had a few problems in the beginning. Our center required parent participation, but it could not accommodate siblings. We had some trouble arranging childcare for our daughters until some church members stepped in to help. There were no initial openings for speech therapy or occupational therapy, and we had a mismatch with the first teacher. After two months, we switched teachers to Elena, who really understands autism and responses to the environment. She helped Mickle experience many first successes and was very patient in helping him learn how to play. We used our private health insurance for the therapies in the end, as this allowed for home visits, which was much easier on our family as a whole.

Even after connecting with a center, we still felt lost with respect to our child's diagnosis. We connected

Continued on page 2

In this issue

| | |
|-----------------------------|---|
| PARENT PERSPECTIVE | 1 |
| VISIONARY THOUGHTS | 2 |
| GREETINGS FROM SANDY LOERCH | 2 |
| STATE AND NATIONAL NEWS | 3 |
| RESOURCES | 4 |
| CONVERSATIONS WITH FAMILIES | 4 |

Greetings to Washington families:

By **Sandy Loerch**,
Director,
ITEIP

I'm excited for this new opportunity to share information with families involved in assisting their child's development through participation in the early intervention system in Washington State. The Family Leadership Team of the Washington State Interagency Coordinating Council (SICC) for Infants and Toddlers with Disabilities, and their Families and I hope this newsletter provides families with:

- ongoing, up to date information on Washington's early intervention services system,
- parent and family rights,
- state and federal regulations,
- early intervention effective and best practices, and
- issues and challenges in the ongoing planning, evaluation and implementation of a family centered, coordinated, interagency early intervention system.

Families are essential and at the core of our statewide efforts. Washington State has active and strong family involvement in early

intervention services. A special thanks to each of you that has spent so many hours on top of your families' schedule and needs to assist with this program.

As we move into the new millennium ITEIP, in coordination with families and state partners, continues its commitment to work on issues of quality, access and effective and best practices, including the provision of services in natural environments. ITEIP has formed a Natural Environments Ad Hoc Committee to begin looking at this important issue. There are many families involved in this committee. The goal of the committee is to develop state guidelines, training and strategies as the state moves towards full implementation of the early intervention section of IDEA (Individuals with Disabilities Education Act).

Ensuring comprehensive family centered early intervention supports requires all of our energy, creative thinking, and commitment. It will take all of us, parents, providers, community members, and agencies working together to continue to develop new ways and improve provision of early intervention services and supports to families.

Together we can reach our common vision for children and families, a coordinated services and support system that allows access and works for all families in need of early intervention services in Washington State.

Family perspectives

CONTINUED FROM PAGE 1

with FEAT (Families for Early Autism Treatment) of Washington. There, we learned about autism, DDD services, and applied behavioral analysis (ABA). FEAT also helped connect us to other parents with children with autism. We also learned about online autism information sites via the Internet. I became active within the birth to three community because I wanted to help other parents connect to each other and to resources. I would like to see more training around the whole autistic spectrum. The professionals we encountered were the strength of Mickie's early intervention experience. Our FRC, teacher, and therapists were very supportive.

Ginger works as an ethnic outreach specialist with the ARC of King County. She is especially active within the Asian community, helping with three support groups for parents. Ginger and her family moved to Hawaii from China in 1989. They resettled in Seattle 6 years later. Ginger is the parent co-chair of the King County Interagency Coordinating Council (ICC), a member of the Stake-holder's Workgroup Subcommittee on children's issues, and a Community Guide for the Division of Developmental Disabilities Family Support Program. In her spare time, she is a Parent-to-Parent volunteer and is active in the Parent Coalition of King County. This year, Ginger wrote and received a Discovery Trust Fund Grant for a summer project with the families of autistic children.

Through my job, I see the need to target ethnic communities. In the Asian community, there is a very low connection rate to services. Many of King County's Asian families are immigrant families who lack knowledge about the early intervention system. Many families face language barriers, financial hardships, and transportation issues. There are also some cultural barriers to overcome. We need to get the word out that it is very acceptable and desirable to seek services for a child with special needs. Targeting community clinics like Seattle's International Clinic would be one way to help accomplish this.

Based on my family's experience, I see a real need for better links with the medical community and more connections with the child care community to help families with siblings. As we enter a new millennium, I would like to see more early intervention service programs offered in a way that addresses the needs and abilities of the whole family; child, siblings, and parents.

Visionary Thoughts

Parents, Service Providers and Policy Makers share their visions for the future as we enter a new Millenium

"I see a future where all children have access to the health care and educational services they require, in a frequency and intensity that will help them develop to their fullest potential. I see a future where families have access to critical information and support services so they never feel isolated or alone trying to raise their child with special needs. I see a future where society-at-large will accept children with disabilities in an inclusive, welcoming circle of community. I see a future of bright possibilities." Julie Ann, parent, King Co.

"My vision for the future is stable funding for the early intervention system." Provider, Snohomish Co.

"In my vision of the future, I won't have to go out and invent recreational opportunities for my son. He will simply join in with the other kids in the neighborhood to play T-ball, soccer, or tag-a-long. He will just be treated like a kid." Terri, parent, Walla Walla Co.

"In the next millennium, I would like to see all children have access to all the funding they require to achieve their full educational potential." Politician, Thurston Co.

"My vision is not to have a need to wear my button that says 'Babies Can't Wait.'" Cassie, Parent

Early Intervention Around the State of Washington

As we move forward into a new millennium, we can look forward to some exiting new trends in the field of early intervention.

- Brain research into the importance of early learning and a stimulating environment is a vibrant movement in our state and in the nation. Washington is updating educators, childcare providers, and policy makers on the new research via the **BrainNet** initiative. Find out more about this research at the ITEIP web site: <http://www.wa.gov/dshs/iteip/iteip.html> or for another interesting look at brain research, check out: <http://www.cast.org>

- **The State Interagency Coordinating Council (SICC)** formed Natural Environments, an Ad Hoc Committee, to work on how best to develop state policies and implementation plans to satisfy the Natural Environments requirements of the federal IDEA regulations. The committee includes parents, educators, birth to three providers, and policy makers. The committee has a busy agenda and a tight timeline in which to accomplish its goals. For more information contact ITEIP at (360) 902-8488.

- **The Family Leadership Team (FLT)** of the SICC is helping to bring Conversations with Families (CWF) to local communities. Members of the SICC and the FLT are going to counties as requested around the state asking families about their successes and concerns with their child's experience within the early intervention system. Family members are also asked for their input on how to make the

system work better for their child. In September 1999, a family picnic and CWF event was held in Wenatchee. Island County held two CWFs in October 1999, one on the north end and one on the south end of the island. Families who wish to participate in future CWF events may contact Cassie Johnston, parent at 1-800-5-PARENT.

- **The SICC** and members of the **FLT** are working with the Developmental Disabilities Council to establish a Family Leadership Institute. While the scope and curriculum are still in process, it is hoped that this team approach to leadership skills and information will get more family members and self-advocates involved in the process of active participation and advocacy.

What's Happening in the Other Washington...

The **Federal Interagency Coordinating Council (FICC)** is the mechanism at the federal level for facilitating interagency coordination of national program resources with the ultimate goal of strengthening the early intervention system for children with disabilities and their families. The FICC is composed of parents, professionals, and policy makers. The mission of the FICC is to:

- Minimize duplication across public agencies.
- Ensure coordination of technical assistance across agencies.
- Ensure provision of early intervention and preschool programs.
- Identify gaps in programs and services across agencies
- Identify barriers to cross-agency coordina-

tion of services to young children with disabilities and their families.

- The **Federal Regulations for the IDEA** (Individuals with Disabilities Education Act) of 1997 were published in the federal register on March 12, 1999. The revisions of the regulations were published on June 24th, 1999. To view the regulations, check out the US Department of Education's web page at: <http://www.ed.gov/legislation/FedRegister/finrule/index.html>
- Recently, OSEP, the Office of Special Education Programs presented its 20th annual **report to Congress**. Here is a brief excerpt:

Children Ages Birth Through Five Served under IDEA:

- Over the past 5 years, the number of infants and toddlers served under Part C has steadily increased from 145,179 on Dec 1, 1992 to 187,348 on Dec 1, 1996. The percentage of the population ages birth through 2 served under Part C rose slightly from 1.54 % in 1995 to 1.65 % in 1996.
- The most frequent setting in which infants and toddlers with disabilities received

services was home (90,275 or 53%), followed by early intervention classroom (47,896 or 28%).

- Over the past 5 years, the number of children served under the IDEA Preschool Grants Program increased from 455,449 during the 1992-93 school year to 559,902 during the 1998-97 school year.
- During the 1995-96, 51.6% of children ages 3-5 with disabilities were served in regular classes, approximately a 1% increase over the % served in regular classes during the previous year.
- The US Department of Education published its Support for CHIP (Children's Health Insurance Program) in the form of a memorandum by Secretary Riley. Local school districts are directed to help provide assistance to help families connect to CHIP resources. The Washington CHIP program provides reduced or no cost insurance to children whose families earn too much to qualify for Medicaid but not enough to afford private insurance. The program is administered at the state level. For more information call toll free 1-877-KIDS-NOW.

State and National Resources

Here is a listing of major agencies and organizations concerning children with special needs and their families. There are many resources for disabilities but the ones below can help link you to many other resources.

WASHINGTON STATE PARENT TO PARENT PROGRAMS

A statewide parent network providing emotional support and information to parents who have children with disabilities or developmental delays.

Phone 1-800-821-5927

Email: stateg2p@earthlink.net

WASHINGTON PAVE (PARENTS ARE VITAL IN EDUCATION)

A statewide parent training and information center that provides parents with information about the Individuals with Disabilities Education Act (IDEA). PAVE also has a newsletter, library and a number of other valuable programs. For more information access their website at:

<http://www.washingtonpave.org> or call 1-800-5- parent.

WASHINGTON STATE FATHERS NETWORK (WSFN)

A support and information network for fathers who have children with special health care needs.

For more information access their website at <http://www.fathersnetwork.org> or call James May at (206) 747-4004

THE WASHINGTON SIBLING SUPPORT PROJECT

This program is dedicated to the interests of brothers and sisters of people with special health care and developmental needs. For more information call 206-527-5711, email dmeyer@chmc.org or visit the website at: <http://www.cchmc.org/departmt/sibshop>

FAMILY VOICES OF WASHINGTON

Provides information to families on healthcare policy and is part of a national coalition of family members speaking on behalf of children with special health care needs. For more information contact Judie Ebbert Rich at 360-866-8254, email familyvoices@olywa.net or check out their great national website: <http://www.familyvoices.org>

THE ARC OF WASHINGTON STATE

Since 1936, The ARC of Washington has been a leader in the development of services and programs for people with developmental disabilities such as, autism, cerebral palsy, mental retardation, epilepsy and related neurological disorders which occur before age 18. Call (360) 357-5596 or email:

arcal@earthlink.net

INFANT TODDLER EARLY INTERVENTION PROGRAM (ITEIP)

This website provides information about services for infants and toddlers, age birth to three, with disabilities and/or developmental delays, and their families in Washington State and has many helpful links to other state and national resources.

Website: <http://www.wa.gov/dshs/iteip/iteip.html>

HEALTHY MOTHERS HEALTHY BABIES

This resource has information about parenting, child development and health information.

Call 1-800-322-2588 or access the website at: <http://www.hmhbwa.org>

ACCESS WASHINGTON RESOURCE DIRECTORY

This is a directory of services for citizens of Washington State. This directory provides access to 22 different types of agencies/ organizations for food clothing, housing, counseling education, employment medical, disability and more.

Website: <http://www.awrd.org>

THE FAMILY VILLAGE

This is a global community, a vast clearing house, "that integrates information, resources and communication opportunities on the Internet for people with disabilities and their families. Family Village is a must see website at: <http://familyvillage.wisc.edu/index.htmlx>

THE NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH DISABILITIES (NICHY)

This is a national information and referral center that provides information on disabilities and disability-related issues for families, educators and other professionals. This is a good resource for families. You can reach them at their toll free number 1-800-695-0285 or their website <http://www.nichy.org/>

NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE SYSTEM (NEC*TAS)

NEC*TAS is a national technical assistance consortium working to support states and others to improve services and results for young children with disabilities and their families. This is a good site to get information on the Federal Interagency Coordinating Council. You can access their website at:

<http://www.nectas.unc.edu>

NATIONAL PARENT NETWORK ON DISABILITIES (NPND)

Established to provide a presence and national voice for parents of children, youth and adults with special needs. Works to influence and affect policy issues concerning people with disabilities and their families. Contact NPND by phone at 202-463-2299 or go the website <http://www.npnd.org/>

NATIONAL PARENT INFORMATION NETWORK (NPIN)

The National Parent Information Network provides information to parents and those who work with parents to foster the exchange of parenting materials. Their website is: <http://npin.org>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC. (NORD)

NORD is the only organization of its kind, a unique federation of more than 140 not for profit voluntary health organizations serving people with rare disorders and disabilities. This organization is dedicated to helping people with rare disorders. Their website is <http://www.rarediseases.org/>

ZERO TO THREE

A national organization dedicated to helping infants, toddlers and their families best navigate the earliest years of life. Their bulletin "Zero to Three" is published six times a year and excerpts are available online. Contact their website at:

<http://www.zerotothree.org/> or call (202)-638-1144

Conversations with Families

A Conversation with Families and SICC meeting was held September 22-23, 1999 in Wenatchee. Conversations with Families was held at the Walla Walla Point Park. Seventy participants attended and the children were treated to a puppet show, courtesy of Wenatchee Parent to Parent. Thanks to the Chelan/Douglas County Interagency Coordinating Council and Wenatchee United Cerebral Palsy Center, who helped coordinate this event for families.

*Conversations with Families
September 1999
Wenatchee*



FLT Members— Congratulations on your Award!!!!

Congratulations to Ronda McElroy, Family Leadership Team member from Snohomish County. Ronda recently received the JC Penney Golden Rule Award for outstanding volunteer efforts in her community.

Congratulations to Judie Ebbert Rich and Cassie Johnston, Family Leadership Team members from Olympia. Judie and Cassie, along with other coordinators from Family Voices Region X, received the 1999 Family Voices National Award for their teamwork and collaboration on behalf of Children with Special Health Care Needs.



PLEASE SEND ALL NEWSLETTER CORRESPONDENCE TO THE ATTENTION OF:

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Family to Family Bulletin is produced by the Family Leadership Team which is a standing committee of the Washington State Infant Toddler Early Intervention Program's (ITEIP) State Interagency Coordinating Council (SICC). ■ The mission of the Family Leadership Team is that families are represented at all levels of the state's early intervention system for children with developmental delays, age birth to six. ■ The mission of ITEIP is to work with Tribes, state agencies, & local communities to assure that all eligible infants & toddlers (birth to 3 years old) with disabilities/delays & their families in Washington State have access to individualized, quality early intervention services in accordance with the Individuals with Disabilities Education Act (IDEA), Part C.

Editorial Board Members: Sandra Lund, Paul Ellegood, Gigi Igama, Cassie Johnston, Karen Lindsay, Sandy Loerch & Glen Turner. **Correspondent-at-large:** Julie Ann Avila.

Staff: Kathy Blodgett.

Please ADD ME TO THE
DIRECT MAILING LIST FOR
FAMILY-TO-FAMILY BULLETIN

MAIL THIS REQUEST TO: CASSIE JOHNSTON,
6316 S 12TH STREET, TACOMA, WA 98465
TELEPHONE: 1 (800) 5 PARENT

NAME

ADDRESS (STREET, CITY, ZIP CODE);

PHONE NUMBER

FAX (OPTIONAL)

E MAIL (OPTIONAL)

AGE OF CHILD



WASHINGTON PAVE
6316 S 12TH STREET, TACOMA, WA 98465